

Prevalence of unmet needs for spasticity management in care home residents in the East

Midlands, United Kingdom: a cross-sectional observational study

L Edwards¹, B Ellis², C Donnellan³, H Osman⁴, N Haboubi⁵, M Jones⁶, W Sunman⁷, L Pinnington⁸, M Phillips⁹

1 = Clinical Associate Professor and Honorary Consultant in Rehabilitation Medicine, University of Nottingham

2 = Senior Lecturer in Physiotherapy, Oxford Brookes University

3 = Specialist Neurophysiotherapist, Linden Lodge Neurorehabilitation Unit, Nottingham University Hospitals NHS Trust

4 = Consultant in Rehabilitation Medicine, The Walton Centre NHS Trust and The Royal Liverpool and Broadgreen University Hospitals NHS Trust

5 = Consultant in Rehabilitation Medicine, Nottingham University Hospitals NHS Trust

6 = Medical Statistician, Derby Clinical Trials Support Unit, University Hospitals of Derby and Burton

7 = Consultant Stroke Physician, Nottingham University Hospitals NHS Trust

8 = Associate Professor in Rehabilitation Medicine, Division of Medical Sciences and Graduate Entry Medicine, University of Nottingham.

9 = Consultant and Honorary Clinical Associate Professor in Rehabilitation Medicine, University Hospitals of Derby and Burton

Abstract

Objective: To establish the prevalence of unmet need for spasticity management in care home residents in two counties of the United Kingdom

Design: cross-sectional observational study with a 6-month follow-up arm for participants with identified unmet needs

Setting: 22 care homes in Derbyshire and Nottinghamshire

Subjects: 60 care home residents with upper motor neuron syndrome-related spasticity

Interventions: No intervention. When unmet needs around spasticity management were identified, the participant's general practitioner was advised of these in writing.

Main measures: Resistance to passive movement scale to assess spasticity; recording of: a) presence of factors which may aggravate spasticity, b) potential complications of spasticity, c) spasticity-related needs, d) current interventions to manage spasticity. Two assessors judged the presence or absence of needs for spasticity management and whether these needs were met by current care.

Results: 14/60 participants had no spasticity-related needs; 46/60 participants had spasticity-related needs and of these 11/60 had needs which were being met by current care. 35/60 participants had spasticity-related needs at baseline which were not being met by their current care. These most frequently related to the risk of contracture development or problems with skin hygiene or integrity in the upper limb. Six participants had one or more pressure sores and 35 participants had one or more established joint contractures.

31 participants were available for follow-up. Informing general practitioners of unmet needs resulted in no change to spasticity management in 23/31 cases.

Conclusion: Care home residents in this study had high levels of unmet need for spasticity management.

Keywords: spasticity management, care home residents, unmet need, upper limb

Prevalence of unmet needs for spasticity management in care home residents in the East

Midlands, United Kingdom: a cross-sectional observational study

Introduction

Spasticity is a common and often disabling consequence of a variety of upper motor neuron syndrome conditions, including stroke, multiple sclerosis, and brain and spinal cord injury (1-4). It is characterised by a velocity-dependent increase in muscle tone. It can cause pain and muscle spasms, and can contribute to a range of complications, including contractures and pressure ulcers (5-7). As a consequence, patients with spasticity may experience reduced quality of life and are subject to higher health and social care costs (8, 9).

Optimal treatment of spasticity involves multidisciplinary input, addressing the primary impairment, reducing factors recognised to precipitate or exacerbate spasticity and managing the risk of developing secondary complications (10). However, not all populations can access such specialist multidisciplinary services, leading to inequitable treatment across patient groups. One arguably “neglected” patient population is those people resident in care homes. In the United Kingdom, care homes are divided into two categories – i) residential homes – where people receive help with personal care such as washing and dressing and ii) nursing homes – where residents have more complex needs and require help with personal care and input from a qualified nurse (11). We are unaware of any studies reporting the prevalence of spasticity in care homes in the United Kingdom but studies from the United States of America and the Netherlands provide estimates around 15-20% (12, 13).

It is known that around 25% of United Kingdom care home residents have had a previous stroke (14), the most common cause of spasticity, and that around 13% of stroke survivors are left with disabling spasticity (15). Given the current population of United Kingdom care homes of 421,000 (16), one could estimate that up to 14,000 United Kingdom care home residents may have problematic post-stroke spasticity. Unfortunately, care home residents have been shown to have

less access to healthcare services (including rehabilitation services) than people living in the community (17, 18), despite often having higher levels of need (19). A study from the Netherlands found that out of 77 care home residents with central nervous system disorders, 56 had spasticity, and of those 56, 20 had some level of clinical need which was not being met by their current care (13). A better understanding is required of the range and level of spasticity-related needs experienced by care home residents in the United Kingdom in order to assess if further targeted interventions are warranted.

The primary objective of this study was to establish the prevalence of unmet need relating to spasticity management in a sample of care home residents with spasticity in the East Midlands, United Kingdom. We also sought to investigate whether highlighting these unmet needs to a participant's general practitioner resulted in changes in spasticity management.

Methods

We conducted a cross-sectional, observational study of care home residents in two regions of the East Midlands, United Kingdom, to explore the prevalence of needs for spasticity management and to find out how often these needs were met. The study protocol was approved by Nottingham 1 Research Ethics Committee (REC 12/EM/0060).

Care homes were identified from local directories (Derbyshire Care Services Directory 2013/2014 and Nottinghamshire County Council Care and Support Services Directory 2013/2014), and their managers were invited to participate in the study by letter followed up by telephone call (see figure 1). Care home managers who did not respond to the letter were telephoned to ascertain their level of interest. Once a care home manager had agreed to participate in the study, they or a nominated senior member of nursing staff at the care home were identified as liaison for the study. This member of staff had responsibility for suggesting potential participants to study staff, based on medical history and clinical presentation.

Care homes that specialised in caring for residents with neurological conditions as well as those that did not were both invited to participate in the study. However, to avoid a disproportionate number of participants being recruited from specialist neurological care homes we decided to recruit no more than 10 participants from each care home. In cases where more than 10 potential participants were identified by care home staff, the potential participants were assigned a number in sequence (based on their surnames, in alphabetical order), and then a random number generator was used to select 10 participants.

Participants were invited into the study based on the following eligibility criteria:

- Inclusion criteria: upper motor neuron lesion with subsequent spasticity; aged over 16; permanently resident in care home

- Exclusion criteria: primary diagnosis of dementia or Parkinson's disease; on end of life care pathway; unable to gain consent or assent; absence of spasticity on examination

Participants with mental capacity to do so provided written informed consent. Participants who lacked capacity and who could not give consent were recruited if informed assent was obtained from a consultee, such as a family member, acting on the participant's behalf.

Participants were recruited and assessed between September 2014 and August 2015 by members of the study team (LE, BE). All participants meeting the eligibility criteria underwent assessment by a neurological physiotherapist (BE) and rehabilitation medicine specialist registrar (LE) using an assessment proforma. The assessment proforma was developed collaboratively by a focus group of clinicians consisting of a neurophysiotherapist, two rehabilitation medicine consultants, one stroke medicine consultant and one rehabilitation medicine specialty registrar. All group members were experienced in treating patients with adult spasticity and had worked in spasticity management for between 4 and 16 years. The proforma was based on published literature, including the then current United Kingdom Royal College of Physicians clinical guidelines for the management of spasticity in adults with botulinum toxin (20). The proforma was designed to gain a snapshot of each participant's clinical presentation, their need for management of spasticity and whether this need was being met.

Data collected in the proforma included:

- Participant demographic and clinical details such as medical diagnosis causing spasticity, co-morbid conditions, language impairment, method of transfer (Table 1)
- Assessment of cognitive function using the Abridged Mental Test-4, a rapidly administered, 4-question screening test for cognitive impairment, scored between 0 (lowest score indicating greatest impairment) and 4 (highest score indicating least impaired) (21) (Table 1)

- Level of independence in activities of daily living using the Barthel Index (a 10 item scoring system around different activities of daily living, with scores ranging from 0 (totally dependent) to 10 (totally independent) (22) (Table 1)
- Presence of spasticity assessed by REPAS in upper and lower limbs. REPAS is a summary rating scale for REsistance to PASSive movement, with a total score and regional body subtest scores, based on the Ashworth Scale with additional guidelines for test administration and scoring. The REPAS measures resistance in 8 upper limb and 5 lower limb joints, scored between 0-4 at each joint, with total scores ranging between 0 (no spasticity identified at any joint) to 104 (increased tone limiting passive movement to less than ¼ of that expected at each joint assessed) (23) (Table 1)
- Presence of complications which could result from the presence of spasticity such as pressure sores, contractures or pain (Table 1)
- Presence of noxious stimuli known to exacerbate spasticity (Table 2)
- Current treatments or interventions being received by participants that could treat spasticity and influence the clinical needs identified (Table 3)
- Assessment of clinical need for spasticity management (such as tightly flexed fingers which could result in breakdown of skin and difficulty with washing hand). When there was a need for spasticity management but no intervention in place this was designated as an “unmet need” for spasticity management (Table 4).

The assessment pro-forma was trialled with a small number of patients in a spasticity management clinic in Nottingham to ensure the form was easy to use and captured relevant information.

The study assessment team assessed the participants together and reached agreement on any areas of subjective opinion (e.g. whether a need was currently met or unmet). Assessments were carried out in the care homes, with permission to access the care homes being granted by senior care home

staff. Data were collected from the participants' care home records (e.g. details of medications), from direct questioning of participants / consultee / care home staff (e.g. Barthel index) and from examination by the study team (e.g. presence and severity of spasticity).

When unmet needs were identified, a letter was written to the participant's general practitioner to inform him or her of the nature of the needs. After six months, the care home was contacted via telephone to ask the nominated senior member of staff about any alterations made to spasticity-related management plans during the intervening period to address any of the unmet needs highlighted (for example changes to medication appropriate to the needs highlighted, therapy input, equipment provision or specialist referrals).

Data handling and statistical analysis

A target sample size of 97 participants with spasticity was calculated using nQuery Advisor 6.01 based on an assumption that the proportion of participants with unmet needs for spasticity management out of those with spasticity was 50% with a precision of +/-10% at 95% Confidence Interval.

All statistical analyses were performed by the study statistician using Stata/IC v11.0. The primary outcome (proportion of participants with spasticity who had unmet needs) was presented with its 95% Confidence Interval. Continuous variables (age, Abbreviated Mental Test score, Resistance to Passive Movement Scale, Barthel score, number of noxious stimuli, total number of interventions) were tested for normality using skewness and kurtosis tests and by reviewing histogram plots. The normally distributed continuous variables were then presented as means with 95% Confidence Intervals for the "Spasticity" population, the "Spasticity with Needs" population and the "Spasticity

with Unmet Needs” population, which were then compared using the p-value of an Analysis of Variance test to assess statistically significant difference between the three groups.

Those continuous variables that were not distributed normally were presented as medians (with Interquartile Ranges) for the same three populations, which were then compared using the p-value of a Kruskal-Wallis test to assess statistically significant difference between the three groups. The categorical variables (gender, type of care home, diagnosis, co-morbidities, mobility, method of transfer, language impairment, muscle spasms, noxious stimuli, intervention types) were presented as frequencies (with percentages) for the same three populations, which were then compared using the p-value of a chi-squared test to assess statistically significant differences between the three groups. Fisher’s Exact tests were used to assess if having unmet spasticity needs was independent of each categorical variable. Spearman’s and Pearson’s correlation coefficients were used to assess if having unmet spasticity needs was correlated with each continuous variable.

Results

Recruitment and retention of care homes and participants through the study are summarised in the flow chart in Figure 1. A total of 438 care homes were invited to participate in the study. The majority declined ($399/438 = 91\%$). A total of 39 care homes agreed to participate and 386 residents were screened for possible inclusion. A small number of residents declined to participate and three were on the end-of-life care pathways. However, the most common reason for exclusion was because the resident did not have an upper motor neuron syndrome, and care home staff had misidentified joint stiffness (commonly due to arthritis) as spasticity. Unfortunately, the exact numbers of individuals who were excluded due to each factor are not available.

In total, 60 participants with spasticity met the inclusion criteria and underwent full assessment. Demographic and clinical details of the participants are presented in Table 1. Diagnoses of participants were as follows: stroke (29 participants), brain injury (11), multiple sclerosis (7), cerebral palsy (6), spinal cord injury (3), spinocerebellar ataxia (2), brain metastases (1), progressive supranuclear palsy (1).

The participants were a dependent population, with only two participants able to walk, whilst the remainder used a wheelchair (52) or were entirely restricted to bed (six). Four participants could transfer independently, whilst the remainder needed assistance or transfer aids.

“Noxious stimuli” which act as aggravating factors for spasticity, were present in 45/60 (75%) participants. More than one noxious stimulus was present in several participants with a range of 0-5. See Table 2 for details.

Complications which could result from the presence of spasticity were present in many participants. Joint contractures were identified in 35 participants ($35/60 = 58\%$). Pressure ulcers were identified in six participants ($6/60 = 10\%$). A total of nine pressure ulcers were present in these six participants – three sacral, two on the heel, and one each at elbow, shin, ankle and antecubital fossa. Five ulcers

were grade 1 (non-blanchable erythema); two were grade 2 (partial thickness) and two could not be classified as the base was not visible. In the opinion of the assessors, spasticity was felt to have contributed to the development or presence of the pressure ulcer in all but one case.

Spasticity-related interventions received by participants are shown in Table 3. Interventions most commonly provided were podiatric review (56/60 = 93%), appropriate seating (48/60 = 80%), provision of a cushion (48/60 = 80%) and regular analgesia (46/60 = 77%).

Spasticity-related needs were identified in 46/60 (77%) participants. In 9 of these cases, all needs were being met by current care. However, in the remaining 35, spasticity-related needs were not being met by current care (see Table 4), giving a prevalence of participants with spasticity who had unmet needs at baseline of 59%, with 95% Confidence Intervals of 46-72%. Mean (SD) of number of needs per participant in the study population was 4.9 (3.7). Mean number of unmet needs was 2.4 (2.7) per participant. Needs relating to upper limb were more frequently identified than needs relating to lower limb or trunk.

The most frequent unmet need relating to spasticity related to management and prevention of contracture and related impact on passive care needs. Contracture avoidance and management in the upper limb was the most commonly identified unmet need (26/60 participants (43%)), followed by management of skin hygiene and integrity in the hand (22/60 (37%)). Unmet needs relating to management and prevention of contracture in the lower limb were slightly less common than in upper limb, occurring in 17 participants (28%).

In contrast, certain spasticity-related needs were regularly met. Difficulty with dressing due to the presence of spasticity was a need in around half of participants (lower limb 25/60 (42%), upper limb 34/60 (57%)). However this need was usually met by care home staff, with no additional benefit considered likely from further management, resulting in a low level of unmet need (lower limb 2/60 (3%), upper limb 3/60 (5%)).

Analysis with correction for multiple comparisons revealed a weakly positive correlation between total number of unmet needs and age (Pearson's correlation co-efficient 0.395; $p=0.009$). There was a weak negative correlation between the total number of unmet needs and the number of spasticity-related interventions (Pearson's correlation co-efficient -0.364; $p=0.027$) (see Figure 2). Diagnosis of stroke had a statistically significant association with unmet needs ($p=0.01$). No other statistically significant associations were detected between any potential confounding categorical or continuous variables and the presence of unmet spasticity needs (all p values >0.05).

For the 35 participants with identified unmet needs, their general practitioner was informed via letter of their needs for spasticity management. Six months after this, 31 participants were available for follow-up as shown in the flow chart in Figure 1. In eight participants ($8/31 = 26\%$), one or more interventions had been put in place to address the spasticity-related needs identified. Some participants had multiple interventions, giving a total of 14 new interventions across these eight participants. These included physiotherapy review (4), new splints (2), new wheelchair (2), new wheelchair cushion (2), new wheelchair pommel (1), provision of T-roll to assist positioning (1), referral to rehabilitation medicine clinic (1) and referral to spasticity management clinic (1). In the remaining 23 participants ($23/31 = 74\%$), no further actions related to spasticity management had been taken.

Discussion

This United Kingdom-based cross-sectional study examined the prevalence of unmet need for spasticity management in care homes in two regions of the East Midlands. This is the first study of this kind, to our knowledge, to have been conducted in the United Kingdom.

In the 60 participants recruited, there was a high level of spasticity-related need and, furthermore, the majority of these needs were not being met by current care. Spasticity resulted from stroke in 48% of participants, with the remainder being comprised of individuals with various conditions including brain injury, multiple sclerosis, cerebral palsy and spinal cord injury. The most frequent unmet needs relating to spasticity were effective management of skin hygiene and integrity of the hand, and management of contractures in the upper limb and lower limb. Aggravating factors for spasticity were present in three quarters of all participants with spasticity. Complications which could result from spasticity were found including upper and lower limb contractures and pressure ulcers. Spasticity-related interventions received by study participants targeted some aggravating factors (for example management of toe nails and pain) or were related to passive care such as appropriate wheelchair and cushion. There were only a few instances of review by specialist consultant or the use of botulinum toxin. Highlighting unmet needs to participants' general practitioners, in the majority of cases, resulted in no change to participants' management, such that after six months, around three quarters of participants still had significant levels of unmet need and remained at risk of a worsening of spasticity-related complications.

The assessments for association between unmet needs and age and between unmet needs and number of interventions were both shown to be statistically significant. However, as these were exploratory analyses, further studies will be required to determine if age or number of interventions can be used as predictors of number of unmet needs. We feel that the management of spasticity in care homes is an area that needs further research.

Unmet need for spasticity management in care home residents has been highlighted in other studies. Meijer and colleagues in the Netherlands (13) assessed the prevalence, impact and treatment of spasticity in care home residents with central nervous system disorders. They used the Modified Ashworth Scale as a measure of spasticity as well as a wide range of bedside tests such as examination of reflexes, coordination, sensation and motor performance. Participant demographics were similar between the Meijer study and our study. One third of patients with spasticity in Meijer's study were felt to have unmet need, characterised as "treatment indication". Needs were classified differently, and the most common indications for treatment were for "easier caring" and symptom (pain / cramps / spasm) relief, so it is difficult to compare this directly with our study. Furthermore, Meijer and colleagues suggested specific treatment courses in the 20 patients they identified with unmet needs, although no data were provided about the outcomes of these recommendations (13). Directly comparing the two studies, Meijer et al found unmet need in 20/56 (36%) participants versus unmet need in our study of 35/60 (58%). However, caution must be exercised when comparing care homes between countries, as the term can encompass subacute care facilities (with integrated rehabilitation) through to geriatric hospitals and hospices, with widely varying members of staff (24). It is difficult to compare international data without clearer definitions of the facilities and populations involved.

Care home residents are recognised to have significant difficulties in accessing rehabilitation and other specialist services (18, 25-27), despite their needs, almost by definition, being greater than those individuals living in their own homes (19). Care home residents with spasticity often have cognitive and communication difficulties which make it more difficult for them to express their needs and consequently they may receive inadequate symptom management unless they are regularly monitored by experts (28, 29). Our study highlighted that very few participants received input from specialist consultants or spasticity management services. Botulinum toxin, which is effective for focal spasticity, was accessed by only 3 participants in our study.

Consistent pathways need to be developed to ensure residents of care homes with spasticity can access spasticity management services in a timely manner (30). The United Kingdom Royal College of Physicians guidelines for management of spasticity in adults (10) highlight the need for treatment at home for some individuals who are less able to travel, but does not explicitly mention care home residents – this may benefit from being addressed in future revisions.

Predictive factors could help identify care home residents who may need active spasticity management, certainly in the post-stroke population. Predictive factors in stroke include severity of paresis (31) and early presence of spasticity in the upper limb (32). Accurate prediction helps early treatment and assists rehabilitation planning. The presence of upper limb spasticity at four weeks post-stroke has shown to be a significant predictor for severe spasticity at twelve months post-stroke (32). The length of stay of people with stroke in the acute hospital stroke services where this study was located are as follows: median length of stay in Derby is 7.5 days (interquartile range 3.1 – 19.2 days) and in Nottingham is 7.6 days (interquartile range 1.4 – 24.4 days) (33). Referral to spasticity services according to presence of spasticity at four weeks would seem to be better placed coming from the community stroke therapy teams who in-reach into care homes within this timeframe. Referral could facilitate early access to specialist assessment and botulinum toxin (34). It is less clear how other client groups (for example people with multiple sclerosis or traumatic brain injury) would be referred but attention needs to be focussed on this question.

Our study revealed a substantial amount of unmet needs for spasticity management for “passive function” goals such as maintaining range of movement in limbs and minimising contracture development (10). Contractures are characterised by a reduction in joint range of motion or an increase in resistance to passive joint movement (35). Contractures have substantial impact on quality of life. Immobility predisposes an individual to develop a contracture whether they have a neurological condition or not (36). Ada *et al* followed individuals with stroke up to 1 year and concluded that spasticity can cause contracture (5). However, work by McGibbon *et al* in traumatic

brain injury, spinal cord injury and cerebral palsy suggests that there is not is a clear association between spasticity and contracture (37).

Passive stretches are ineffective to treat contractures (38). Prevention is the preferred option. Input from specialist spasticity management teams could optimise management. Allison *et al* suggest that for people with severe paresis in the arm, education about management of the arm to reduce secondary complications such as contracture could be an effective intervention (39). In addition, early targeting of spasticity post-stroke may help minimise contracture development and reduce the difficulty of caring for the arm over the longer term (39).

Another “passive function” goal with unmet needs found in our study was preserving skin integrity and maintaining hygiene. There is an increased risk of developing or worsening of existing pressure ulcers in patients with neurological conditions and patients with contractures (40, 41). It is important that the vulnerable care home population have access to effective treatments to manage spasticity to help minimise secondary complications such as pressure ulcers.

There were significant problems around recruitment into this study and we failed to reach our target sample size. Less than 9% of invited care homes agreed to participate. It was difficult eliciting any responses from most care homes. There are likely to be a number of factors contributing to this. Firstly, care homes are stressful places to work, with high levels of under-staffing and staff turnover (42, 43), so it is perhaps unsurprising that a research study invitation would not be seen as a priority. In this small study, there was no opportunity for reciprocity, such as training or educational opportunities for staff, so perceived disadvantages of participation (time consuming, disruptive, potential for criticism) would not have been countered by any advantages, which may have encouraged more participation.

After gaining access to care homes, the identification of suitable participants was limited by a lack of understanding of study criteria by care home staff, who frequently suggested participants who had

issues of “stiffness” rather than “spasticity”, despite the study team’s best efforts to clarify the inclusion criteria. It is possible that inviting care home staff to educational days, or providing extra resources, before the study started might have ameliorated this (36), but in a small study, this was not feasible.

Following identification of suitable participants, the next barriers were around obtaining consent or assent. There are high rates of apathy and depression in care home residents, which can make potential participants less willing to consider participation in a study (44, 45). For those potential participants without the capacity to consent to participation, identifying and then liaising with next of kin represented further logistical challenges, and it is possible that consultees may have been less willing to provide assent to a study where there were no immediately identifiable benefits to their relative.

These problems are not new or unusual. Conducting research in care homes (46), and particularly through consultees (47), is recognised to be challenging, although networks are being established to facilitate future research projects, such as the ENRICH (Enabling Research In Care Homes) toolkit, and we hope to engage with this for further work. On a positive note, those care homes that did participate gave us positive feedback – particularly when it was felt that participants’ involvement in the study had led to improvements in care, such as access to therapy or wheelchair services.

Our study had a number of limitations. The recruitment strategy aimed to gain a representative sample of care homes. However only a few care homes agreed to be involved. It is possible that the small number of care homes agreeing to participate may have been more interested or pro-active in spasticity management, and therefore the results obtained in this study should not be extrapolated beyond this sample. Our attempt to gain participants from different care homes across the two regions caused us to limit the total number of participants from each care home to 10. This resulted in 48% of our sample of participants with spasticity being due to stroke. A different recruitment strategy would be required for us to gain greater numbers of participants with multiple sclerosis,

traumatic brain injury, cerebral palsy and other conditions, as potential participants with these conditions tended to be more predominantly clustered in a smaller number of more specialist care homes. Taking a larger number from these homes would have included more people with alternative diagnoses, but would have been less reflective of the “general” care home population.

The design of our study was cross-sectional and therefore gave no indication of the time course of development of needs and unmet needs. Future research would be valuable to understand the differing needs for spasticity management along the trajectory of different neurological conditions.

The data collection pro-forma we used was trialled on just a few patients. Ideally, we would have completed a more formal evaluation but were unable to do this in the timescale of this study. It is also important to acknowledge that the presence or absence of “unmet needs” relied on the judgement of the assessing team.

We wrote to the general practitioner of each participant with unmet needs for spasticity management providing summary information of these needs. It was not feasible to do more than this within the context of this study. However, a future study would benefit from further consideration of how to ensure the participants’ needs for spasticity management could be met. In view of the highly pressured and increasing workloads of general practitioners, the involvement of the community neuro-rehabilitation therapists responsible for the residents’ care home might be a good option to consider.

Whilst acknowledging the limitations of our study, the findings indicate a high level of need for spasticity management in care home residents in two regions of the United Kingdom. Most of these needs were not being met by current care plans.

Clinical Messages

- In this sample of care home residents with spasticity in the East Midlands, United Kingdom, there was a high level of unmet need for spasticity management.
- Most spasticity-related needs remained unmet 6 months after informing participants' general practitioners of these needs.
- Gaining access to the care home population and identifying suitable study participants within this population proved very challenging.

Acknowledgements

The authors are grateful to all study participants, next of kin / consultees and care home staff for their willingness to contribute to this work.

The authors are grateful to Professor Derek Wade for his valued input into the revisions of the manuscript.

LE and BE wrote the paper, recruited the patients, obtained, recorded and interpreted the data; MJ analysed and interpreted the data; NH, CD, MP, HO and WS designed the study; LE, BE, LP, WS and CD edited the paper; MP and LP had overall study oversight.

Support: LE was in receipt of an NIHR Academic Clinical Fellowship at the time of the study. The authors would like to thank Mertz pharmaceuticals for an educational grant which allowed this project to be carried out.

Declaration of conflicting interests: none

References

1. Urban PP, Wolf T, Uebele M, Marx JJ, Vogt T, Stoeter P, et al. Occurrence and clinical predictors of spasticity after ischemic stroke. *Stroke*. 2010 Sep;41(9):2016-20. PubMed PMID: 20705930.
2. Rizzo MA, Hadjimichael OC, Preiningerova J, Vollmer TL. Prevalence and treatment of spasticity reported by multiple sclerosis patients. *Multiple sclerosis*. 2004 Oct;10(5):589-95. PubMed PMID: 15471378.
3. Holtz KA, Lipson R, Noonan VK, Kwon BK, Mills PB. Prevalence and Effect of Problematic Spasticity After Traumatic Spinal Cord Injury. *Archives of physical medicine and rehabilitation*. 2017 Jun;98(6):1132-8. PubMed PMID: 27780743.
4. Sunnerhagen KS, Opheim A, Alt Murphy M. Onset, time course and prediction of spasticity after stroke or traumatic brain injury. *Annals of physical and rehabilitation medicine*. 2018 May 16. PubMed PMID: 29753889.
5. Ada L, O'Dwyer N, O'Neill E. Relation between spasticity, weakness and contracture of the elbow flexors and upper limb activity after stroke: an observational study. *Disability and rehabilitation*. 2006 Jul 15-30;28(13-14):891-7. PubMed PMID: 16777777.
6. Malhotra S, Pandyan AD, Rosewilliam S, Roffe C, Hermens H. Spasticity and contractures at the wrist after stroke: time course of development and their association with functional recovery of the upper limb. *Clinical rehabilitation*. 2011 Feb;25(2):184-91. PubMed PMID: 20921028.
7. Milinis K, Tennant A, Young CA, group TOs. Spasticity in multiple sclerosis: Associations with impairments and overall quality of life. *Multiple sclerosis and related disorders*. 2016 Jan;5:34-9. PubMed PMID: 26856941.
8. Ganapathy V, Graham GD, DiBonaventura MD, Gillard PJ, Goren A, Zorowitz RD. Caregiver burden, productivity loss, and indirect costs associated with caring for patients with poststroke spasticity. *Clinical interventions in aging*. 2015;10:1793-802. PubMed PMID: 26609225. Pubmed Central PMCID: 4644168.

9. Stevenson VL, Gras A, Bardos JI, Broughton J. The high cost of spasticity in multiple sclerosis to individuals and society. *Multiple sclerosis*. 2015 Oct;21(12):1583-92. PubMed PMID: 25623252.
10. London RCoPo. Spasticity in Adults, Management using botulinum toxin. In: Physicians RCo, editor. London2018.
11. NHS. Care Homes 2019 [cited 2019 19/03/2019]. Available from: <https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/care-homes/>.
12. Gill C, Bryant J, Charles P, Schnelle JF, Simmons S. Prevalence and impact of spasticity in a single nursing home. *Archives of physical medicine and rehabilitation*. 2008;89:e52.
13. Meijer R, Wolswijk A, Eijdsden HV. Prevalence, impact and treatment of spasticity in nursing home patients with central nervous system disorders: a cross-sectional study. *Disability and rehabilitation*. 2017 Feb;39(4):363-71. PubMed PMID: 26941031.
14. Bowman C, Whistler J, Ellerby M. A national census of care home residents. *Age and ageing*. 2004 Nov;33(6):561-6. PubMed PMID: 15308458.
15. Wissel J, Manack A, Brainin M. Toward an epidemiology of poststroke spasticity. *Neurology*. 2013 Jan 15;80(3 Suppl 2):S13-9. PubMed PMID: 23319481.
16. LaingBuisson. Care homes for Older People market analysis and projections. London: 2016.
17. Steves CJ, Schiff R, Martin FC. Geriatricians and care homes: perspectives from geriatric medicine departments and primary care trusts. *Clinical medicine*. 2009 Dec;9(6):528-33. PubMed PMID: 20095292.
18. Iliffe S, Davies SL, Gordon AL, Schneider J, Denning T, Bowman C, et al. Provision of NHS generalist and specialist services to care homes in England: review of surveys. *Primary health care research & development*. 2016 Mar;17(2):122-37. PubMed PMID: 25939731.
19. Gordon AL, Franklin M, Bradshaw L, Logan P, Elliott R, Gladman JR. Health status of UK care home residents: a cohort study. *Age and ageing*. 2014 Jan;43(1):97-103. PubMed PMID: 23864424. Pubmed Central PMCID: 3861334.

20. London RCoPo. Spasticity in adults: management using botulinum toxin - National Guidelines. London: Royal College of Physicians; 2009.
21. Swain DG, Nightingale PG. Evaluation of a shortened version of the Abbreviated Mental Test in a series of elderly patients. *Clinical rehabilitation*. 1997 Aug;11(3):243-8. PubMed PMID: 9360037.
22. Wade DT, Collin C. The Barthel ADL Index: a standard measure of physical disability? *International disability studies*. 1988;10(2):64-7. PubMed PMID: 3042746.
23. Platz T, Vuadens P, Eickhof C, Arnold P, Van Kaick S, Heise K. REPAS, a summary rating scale for resistance to passive movement: item selection, reliability and validity. *Disability and rehabilitation*. 2008;30(1):44-53. PubMed PMID: 17852258.
24. Sanford AM, Orrell M, Tolson D, Abbatecola AM, Arai H, Bauer JM, et al. An international definition for "nursing home". *Journal of the American Medical Directors Association*. 2015 Mar;16(3):181-4. PubMed PMID: 25704126.
25. Noone I, Fan CW, Tarrant H, O'Keeffe S, McDonnell R, Crowe M. What happens to stroke patients after hospital discharge? *Irish medical journal*. 2001 May;94(5):151-2. PubMed PMID: 11474857.
26. Sackley CM, Gatt J, Walker MF. The use of rehabilitation services by private nursing homes in Nottingham. *Age and ageing*. 2001 Nov;30(6):532-3. PubMed PMID: 11742788.
27. Sackley C, Hoppitt T, Cardoso K, Levin S. The availability and use of allied health care in care homes in the Midlands, UK. *International Journal of Therapy and Rehabilitation*. 2009;16(4):218.
28. Ronning OM, Tornes KD. Need for symptomatic management in advanced multiple sclerosis. *Acta neurologica Scandinavica*. 2017 May;135(5):529-32. PubMed PMID: 27357364.
29. Lam K, Lau K, So K, Tam C, Wu Y, Cheung G, et al. Use of botulinum toxin to improve upper limb spasticity and decrease subsequent carer burden in long-term care residents: a randomised controlled study. *Hong Kong Medical Journal*. 2016;22(Supplement 2):S43-5.
30. Picelli A, Baricich A, Cisari C, Paolucci S, Smania N, Sandrini G. The Italian real-life post-stroke spasticity survey: unmet needs in the management of spasticity with botulinum toxin type A.

Functional neurology. 2017 Apr/Jun;32(2):89-96. PubMed PMID: 28676142. Pubmed Central PMCID: 5507158.

31. Tedesco Triccas L, Kennedy N, Smith T, Pomeroy V. Predictors of upper limb spasticity after stroke? A systematic review and meta-analysis. Physiotherapy. 2019 Jan 11. PubMed PMID: 30745061.

32. Opheim A, Danielsson A, Alt Murphy M, Persson HC, Sunnerhagen KS. Early prediction of long-term upper limb spasticity after stroke: part of the SALGOT study. Neurology. 2015 Sep 8;85(10):873-80. PubMed PMID: 26276377. Pubmed Central PMCID: 4560058.

33. SSNAP. Sentinel Stroke National Audit Programme (SSNAP) audit data April 2017-March 2018 2018 [12 March 2019].

34. Rosales R. Botulinum toxin therapy as an early intervention for post-stroke spasticity: Beyond a functional viewpoint. Journal of the neurological sciences. 2017 Nov 15;382:187-8. PubMed PMID: 29042064.

35. Fergusson D, Hutton B, Drodge A. The epidemiology of major joint contractures: a systematic review of the literature. Clinical orthopaedics and related research. 2007 Mar;456:22-9. PubMed PMID: 17179779.

36. Saal S, Meyer G, Beutner K, Klingshirn H, Strobl R, Grill E, et al. Development of a complex intervention to improve participation of nursing home residents with joint contractures: a mixed-method study. BMC geriatrics. 2018 Feb 28;18(1):61. PubMed PMID: 29490617. Pubmed Central PMCID: 5831216.

37. McGibbon CA, Sexton A, Hughes G, Wilson A, Jones M, O'Connell C, et al. Evaluation of a toolkit for standardizing clinical measures of muscle tone. Physiological measurement. 2018 Aug 8;39(8):085001. PubMed PMID: 30019689.

38. Harvey LA, Katalinic OM, Herbert RD, Moseley AM, Lannin NA, Schurr K. Stretch for the treatment and prevention of contractures. The Cochrane database of systematic reviews. 2017 Jan 9;1:CD007455. PubMed PMID: 28146605.

39. Allison R, Kilbride C, Chynoweth J, Creanor S, Frampton I, Marsden J. What Is the Longitudinal Profile of Impairments and Can We Predict Difficulty Caring for the Profoundly Affected Arm in the First Year Poststroke? *Archives of physical medicine and rehabilitation*. 2018 Mar;99(3):433-42. PubMed PMID: 28866012.
40. Capon A, Pavoni N, Mastromattei A, Di Lallo D. Pressure ulcer risk in long-term units: prevalence and associated factors. *Journal of advanced nursing*. 2007 May;58(3):263-72. PubMed PMID: 17474915.
41. Vanderwee K, Grypdonck M, De Bacquer D, Defloor T. The identification of older nursing home residents vulnerable for deterioration of grade 1 pressure ulcers. *Journal of clinical nursing*. 2009 Nov;18(21):3050-8. PubMed PMID: 19732245.
42. Cousins C, Burrows R, Cousins G, Dunlop E, Mitchell G. An overview of the challenges facing care homes in the UK. *Nursing older people*. 2016 Oct 28;28(9):18-21. PubMed PMID: 27788655.
43. Hussein S, Ismail M, Manthorpe J. Changes in turnover and vacancy rates of care workers in England from 2008 to 2010: panel analysis of national workforce data. *Health & social care in the community*. 2016 Sep;24(5):547-56. PubMed PMID: 25736156.
44. Boorsma M, Joling K, Dussel M, Ribbe M, Frijters D, van Marwijk HW, et al. The incidence of depression and its risk factors in Dutch nursing homes and residential care homes. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry*. 2012 Nov;20(11):932-42. PubMed PMID: 22828203.
45. van Almenkerk S, Smalbrugge M, Depla MF, Eefsting JA, Hertogh CM. Apathy among institutionalized stroke patients: prevalence and clinical correlates. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry*. 2015 Feb;23(2):180-8. PubMed PMID: 24823894.
46. Shepherd V, Nuttall J, Hood K, Butler CC. Setting up a clinical trial in care homes: challenges encountered and recommendations for future research practice. *BMC research notes*. 2015 Jul 16;8:306. PubMed PMID: 26179284. Pubmed Central PMCID: 4504165.

47. Goodman C, Baron NL, Machen I, Stevenson E, Evans C, Davies SL, et al. Culture, consent, costs and care homes: enabling older people with dementia to participate in research. *Aging & mental health*. 2011 May;15(4):475-81. PubMed PMID: 21500014.

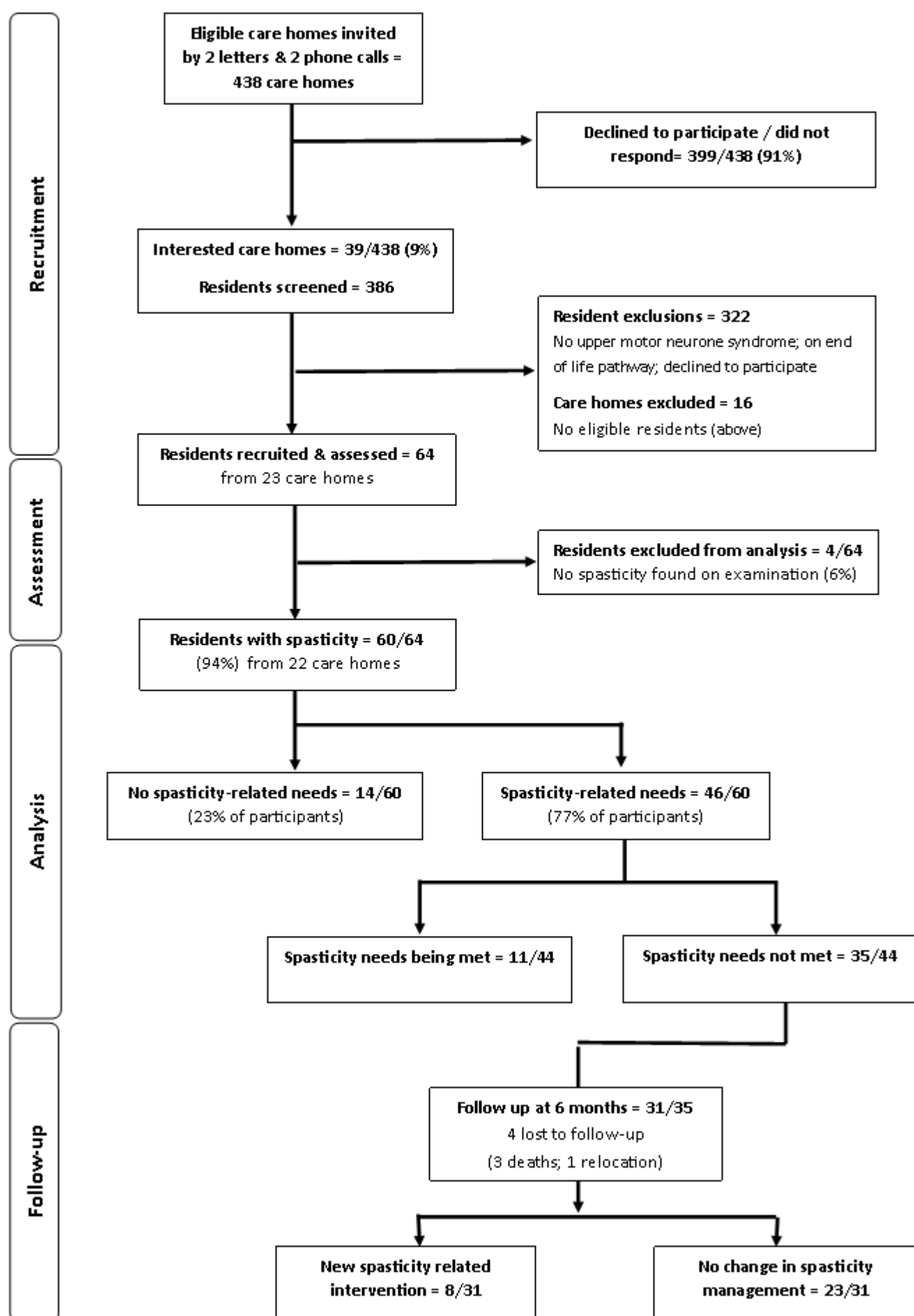
Figure 1: Flow chart of participants and care homes through study

Table 1: Demographic and clinical details of study population of care home residents with spasticity (n=60)

Demographic details	Gender male:female (n)	26:34
	Age: median (IQR)	71 (53-84)
Consent, cognition and dependency	Assent via consultee (n)	26
	Abbreviated Mental Test-4 score: median (IQR)	2 (0-4)
	Barthel Index*: median (IQR)	2 (0-5)
Clinical details	Resistance to Passive Movement score: median (IQR)	22 (9-32)
	Presence of muscle spasms (n)	22
	Presence of pressure sores (n)	6
	Presence of joint contractures (n)	35
	Presence of at least one noxious stimulus	45
	Mean number of spasticity-related interventions per participant	8

*note Barthel Index data only available for 58 participants

NB: potential Barthel scores range from 0 (totally dependent) to 10 (totally independent); Resistant to Passive Movement Score from 0 (no spasticity identified at any joint) to 104 (increased tone limiting movement to less than ¼ at each joint assessed)

IQR = interquartile range

Table 2: List of noxious stimuli which are aggravating factors to spasticity and frequency with which these were found in study participants

Source of noxious stimulus	Examples	Number of participants affected out of total of 60
Bladder	Incontinence / catheter-related problems	16
Bowel	Incontinence / constipation	19
Pain	Nociceptive or neuropathic	33
Current infection	Urinary tract or chest	5
Skin / podiatric	Pressure damage / ulceration	6
	Ingrowing toenails	2

Table 3: List of spasticity-related interventions screened for and the numbers of participants who were receiving these interventions at time of assessment

Intervention category	Individual Intervention	Number of participants receiving intervention n (%) (out of total of 60 participants)	Number of interventions received per participant Median (IQR)
Medical / surgical interventions	Spasticity medication (enteral)	23 (38)	0 (0-1.0)
	Botulinum toxin injections	3 (5)	
	Phenol injections	0 (0)	
	Intrathecal baclofen	0 (0)	
	Surgical release	0 (0)	
Physical interventions	Muscle stretching programme (at least 1/week)	21 (35)	2 (0 – 3.3)
	Positioning programme (in bed and/or chair)	29 (48)	
	Bed positioning equipment	18 (30)	
	Splints / orthoses	9 (15)	
	Pressure relieving hoist sling	14 (23)	
	District nurse	5 (8)	
	Community physiotherapist	17 (28)	
	Community occupational therapist	6 (10)	
Management of noxious stimuli	Bowel management programme	29 (48)	2 (2.0 – 3.0)
	Regular analgesia	46 (77)	
	Bladder care programme	18 (30)	
	Podiatry review	56 (93)	

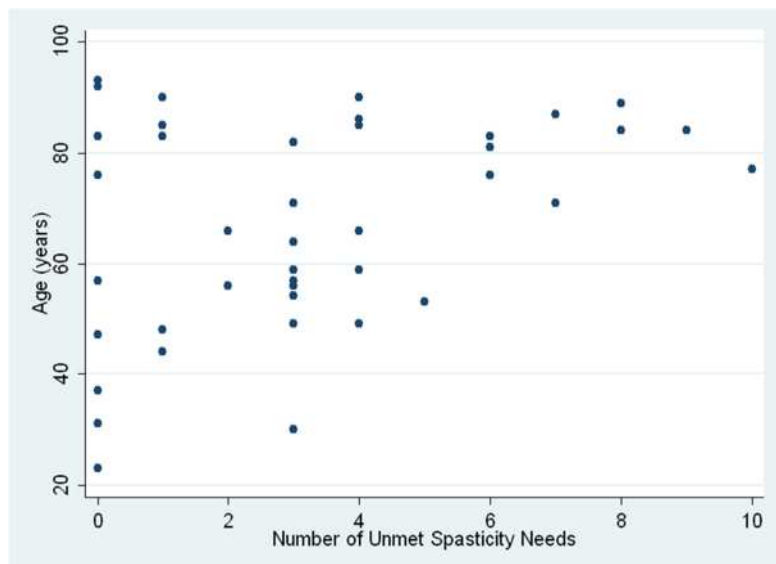
Seating	Appropriate seating	48 (80)	3 (2.0 – 3.0)
	Appropriate cushion	48 (80)	
	Wheelchair services	33 (55)	
Specialist review	Specialist spasticity management professional	7 (12)	0 (0 – 1.0)
	Tissue viability nurse	6 (10)	
	Orthotist	6 (10)	
	Rehabilitation medicine consultant	8 (13)	
	Stroke physician	1 (2)	
	Neurologist	4 (7)	
	Neurosurgeon (e.g. for intrathecal baclofen)	1 (2)	
	Orthopaedic surgeon (e.g. surgical release)	1 (2)	

Table 4: List of needs for spasticity management and the frequency that these needs were assessed as being unmet in the study participants

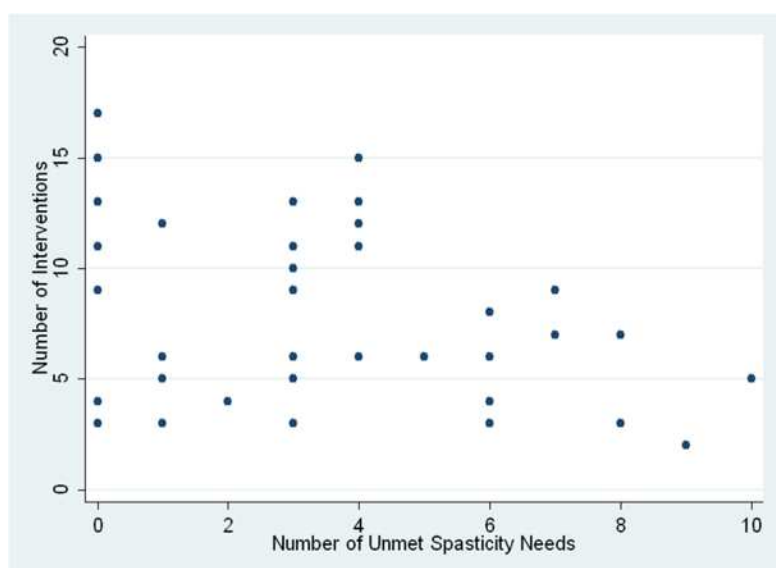
Needs category	Specific Need	Frequency of needs (n=60) n (%)	Frequency of unmet needs (n=60) n (%)
Overall	Any need(s) for spasticity management	46 (77)	35 (58)
Hygiene / skin care / skin integrity	Hand	30 (50)	22 (37)
	Antecubital fossa	7 (12)	3 (5.0)
	Axilla	11 (18)	6 (10)
	Groin/perineum	8 (13)	4 (6.7)
	Ischial tuberosity, sacrum or greater trochanter	15 (25)	10 (17)
	Neck region	3 (5.0)	2 (3.3)
Dressing	Upper limb	34 (57)	3 (5.0)
	Lower limb	25 (42)	2 (3.3)
Postural management	Difficulty positioning in bed	26 (43)	14 (23)
	Difficulty sitting in chair or wheelchair	25 (43)	10 (17)
Pain related to spasticity	Upper limb	13 (22)	8 (13)
	Lower limb	7 (12)	3 (5.0)
	Neck region	0 (0)	0 (0)
Contracture	Upper limb	37 (62)	26 (43)
	Lower limb	30 (50)	17 (28)

	Neck	4 (6.7)	3 (5.0)
Active function limited by spasticity	Upper limb function	6 (10)	3 (5.0)
	Standing, transferring, walking	10 (17)	8 (13)

Figure 2: correlations between continuous variables and total numbers of unmet needs identified in participants.



Spearman's correlation coefficient 0.2336; p 0.028
Pearson's correlation coefficient 0.395; p 0.009



Spearman's correlation coefficient -0.300; p 0.067
Pearson's correlation coefficient -0.364; p 0.027